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IN THE

Supreme Court of the United States

OCTOBER TERM, 1984

MARGARET M. HECKLER, SECRETARY OF HEALTH AND HUMAN SERVICES,

Petitioner,

vs.

AMERICAN HOSPITAL ASSOCIATION, et al.

Respondents.

ON A WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICUS CURIAE OF CARLTON JOHNSON IN SUPPORT OF PETITIONER, MARGARET M. HECKLER

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INTEREST OF AMICUS CURIAE

Carlton Johnson, a black male infant, was born September 12, 1982. At birth, Carlton had myelomeningocele, hydrocephalus, and associated congenital anomalies. Carlton did not receive optimal medical treatment. Instead, he was subjected to a discriminatory selection process that denied him appropriate medical care — surgery, placing a shunt and, later, antibiotics and intravenous fluids. Carlton, unfortunately, did not meet the intellectual, social, economic, and other nonmedical criteria deemed necessary to provide disabled infants access to proper treatment at Oklahoma Children's Memorial Hospital. He was, therefore, denied beneficial medical treatment and transferred to a nursing care facility. Surprisingly, Carlton survived and a year later the myelomeningocele team at Oklahoma Children's Memorial Hospital reconsidered their initial recommendation for non-treatment. Carlton finally received definitive medical care in January, 1984 — a year and a half after his birth. Further evaluation is necessary to determine the degree of intellectual and physical impairment Carlton suffered as a direct result of the delay in treatment.

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982), is intended to prevent discrimination on the basis of handicap. When Carlton Johnson was denied access to medical treatment because of his handicaps — medical treatment that an infant without disabilities would certainly have been provided — Carlton's civil rights under Section 504 were violated.

The National Legal Center for the Medically Dependent and Disabled, Inc., a support center for the Legal Services Corporation, represents Carlton in a prospective class action litigation against individuals associated with Oklahoma Children's Memorial Hospital who selected Carlton and other disabled children for non-treatment. An allegation that Section 504 was violated by this selection

process is the crucial federal civil rights claim to be raised by Carlton and his class. If Section 504 is held not to apply to discriminatory medical practices, then Carlton will not have this remedy available. This brief is thus offered to illustrate the need for the application of Section 504 to protect infants like Carlton. All parties have consented to the filing of this brief.

SUMMARY OF ARGUMENT

A selection program that qualified some infants for life-saving medical treatment and rejected others, illustrates the compelling need for Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982) (hereinafter cited as "Section 504"), to apply to discriminatory medical practices.

This selection program, implemented by a team of health care professionals at Oklahoma Children's Memorial Hospital, a state institution, was applied to infants with a congenital disability known as myelomeningocele — an opening in the spine. The results of the program over a five year period were reported in medical literature. During this process of selection among children with treatable problems, social, economic, intellectual, and other non-medical criteria were considered before the infant was permitted full access to medical treatment. All of the twenty-four infants subjected to this selection process, and who were recommended for only "supportive care," died. The euphemism, "supportive care" entailed denial of beneficial medical treatment; it consisted of minimal comfort-care, without the use of antibiotics or sedatives. Recommendations for "supportive care" were made for about half of the infants seen, even though these children had the same chance for survival with appropriate treatment as did those infants who were deemed "worthy" of proper treatment.

The plain language of Section 504 was violated twice when these handicapped infants were denied the benefits of medical treatment: 1) when the infant who had a prognosis

for survival with a "significant" handicap was placed in a selection program instead of receiving proper treatment; 2) when an infant in the selection program was evaluated on the basis of social, economic, and intellectual criteria, as well as the degree of the child's physical disability and the economic, intellectual, and emotional resources of the family, in order to determine if the child qualified for treatment.

Carlton Johnson is a black male born with myelomeningocele. Now nearly 3 years of age, he was evaluated by the myelomeningocele team at Oklahoma Children's Memorial Hospital shortly after his birth and shortly after the time of the reported study. Carlton did not meet the social, intellectual, economic, and other nonmedical criteria necessary to qualify him for proper treatment. He was transferred, presumably to die, to an intermediate nursing care facility.

One month later, Carlton returned to Oklahoma Children's Memorial Hospital. He was critically ill, suffering from severe dehydration and an ear infection. Instead of the aggressive therapy that any nonhandicapped child would have received, Carlton was denied the benefits of laboratory tests to monitor his condition, intravenous fluids, and antibiotics. But surprisingly, Carlton improved after rehydration through oral-gastric tube feedings. His infection subsided on its own.

Carlton Johnson's rights under the plain language of Section 504 were violated twice at Oklahoma Children's Memorial Hospital. During his first admission, he was subjected to an evaluation that led to a recommendation for "supportive care" only, which discriminatorily denied him access to beneficial medical treatment. During his second admission, Carlton was deprived of appropriate treatment in a life-threatening situation — treatment that would have, without question, been provided to any nonhandicapped infant.

Section 504 must be held to apply to discriminatory

medical practices so that the federal government has the power to investigate and remedy these types of discriminatory conduct. Yet due to the injunction issued by the lower court in this case, the Department of Health and Human Services has been unable to investigate or remedy the situation at Oklahoma Children's Memorial Hospital.

While it is asserted that the final decision for "supportive care" or treatment — actually a decision between life and death — was left to the parents, parents do not have the informational and emotional resources available to them to make a competent decision immediately after the birth of their disabled child. The parents routinely relied on the expertise of the myelomeningocele team; there is no evidence that the parents are told of the nonmedical social, economic, and intellectual criteria considered in making the recommendation. The myelomeningocele team in fact made the decision, not the parents. After a decision for "supportive care" was effectuated and the child died, rights to the companionship, care, and custody of the child were lost. Thus, not only were child's rights discriminatorily denied, but parental rights were also violated.

A recent Act of Congress treats the type of discriminatory conduct evidenced by the selection process at Oklahoma Children's Memorial Hospital as child abuse. But the sole remedy the Act provides is termination of federal funds to state child neglect and abuse agencies that fail to pursue such instances of abuse. Unless Section 504 applies to discriminatory medical practices, the federal government would be compelled to continue funding such discriminatory medical treatment regimens, but be required to terminate funding to state child protection agencies that fail to pursue such instances of child abuse — an absurd and anomolous result.

The federal government must have the power to investigate and remedy allegations of discriminatory medical practices in order to protect both disabled infants and their parents; Section 504 must be available to parents and disabled children to provide them a federal remedy for

medical discrimination. Children like Carlton Johnson are in obvious need of the protection of federal civil rights law. A decision by this Court that Section 504 does not apply to discriminatory medical practices would unjustly deprive the federal government, disabled children, and their parents of this remedy.

ARGUMENT

I. INTRODUCTION

This amicus curiae brief is submitted on behalf of Carlton Johnson, a child who has been subjected to discriminatory medical treatment because of his disability, in support of the position of the United States that Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982), applies to discriminatory medical practices.

The compelling need for the application of Section 504 to discriminatory medical practices shall be demonstrated by description of a selection process, implemented at Oklahoma Children's Memorial Hospital, a state institution, designed to sort out infants for treatment or nontreatment based on projected intellectual status, their ability to walk, and social and economic factors. This selection process has been fully described and discussed in an article authored by several of the health care professionals who participated in it. Twenty-four disabled children subjected to this process died after they were selected for the nontreatment on the basis of criteria that clearly violate the plain language of Section 504. The personal tragedy of Carlton Johnson, who has been subjected to two separate and distinct violations of Section 504 as a patient at Oklahoma Children's Memorial Hospital, will also be described.

By holding that Section 504 does not apply to discriminatory medical practices, the Court of Appeals for the Second Circuit in *American Hospital Association v. Heckler*, No. 84-6211 (2d Cir. Dec. 27, 1984), *cert. granted*, 105 S.Ct. 3475 (1985), effectively forbade the United States

from undertaking any investigative or enforcement action to stop such blatant discriminatory conduct; it foreclosed children with disabilities or their parents from invoking the protection of Section 504 in the face of past or continuing discriminatory medical practices.

If the Second Circuit decision is affirmed by this Court, then Carlton Johnson and and other young disabled children will not have the remedies afforded by Section 504 available to them; the federal government will be impotent to intercede on behalf of these vulnerable infants even in the face of egregiously discriminatory medical practices. Such an absurd and unjust result must be rejected by this Court.

II. THE SELECTION PROCESS AT OKLAHOMA CHILDREN'S MEMORIAL HOSPITAL ILLUSTRATES THE COMPELLING NECESSITY THAT SECTION 504 APPLY TO DISCRIMINATORY MEDICAL PRACTICES.

In October, 1983, a program of early selection for treatment or nontreatment of infants born with myelomeningocele was described in the medical journal *Pediatrics*. Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 Pediatrics 450 (1983) (hereinafter cited as "Gross"). The program was developed at the University of Oklahoma Health Services Center in 1977, and the report encompassed the five year period from 1977 through 1982.

During this five year period, sixty-nine infants were screened; thirty-three were recommended for "supportive care" — an euphemism for denial of beneficial medical treatment — on the basis of intellectual, social, and economic criteria. The twenty-four infants who in fact received "supportive care" all died within 189 days of birth. *Id.* at 452-53.

A. The Selection Process Discriminated Against Infants with Congenital Disabilities.

The selection process applied to infants born with myelomeningocele. A congenital disability, myelomeningocele is characterized by an opening in the spine at which a "sac" protrudes from the body of the child. This sac contains cerebrospinal fluid and nerve roots that would normally be contained within the spinal column. Depending on various factors, including the level of the myelomeningocele on the spine and the extent of nerve involvement, an affected infant might experience loss of lower extremity function and, perhaps, loss of bowel and bladder control. "Optimal treatment [of the myelomeningocele] consists of prompt surgical closure of the skin defect, preferably within 48 hours after birth, to prevent meningeal infection." Nelson, Behrman and Vaughan, *Textbook of Pediatrics* 1562 (12th ed. 1983). "It [myelomeningocele] is one of the most common developmental anomalies of the nervous system; the incidence ranges from 0.2-0.4/1000 births in different population groups.... Little is known about the etiology of myelomeningocele." *Id.* at 1561. If treated, almost all children with myelomeningocele will be ambulatory — they may walk with braces or crutches, or may use a wheelchair. Mental retardation is not directly associated with myelomeningocele if it is properly treated.

Hydrocephalus, a potentially serious anomoly often associated with myelomeningocele, occurs when too much cerebrospinal fluid accumulates within the cranium. If untreated, this condition causes the head to greatly enlarge and damages the developing brain. Treatment of hydrocephalus involves placement of a shunt that drains the excess fluid into another body cavity, most commonly the abdomen. *Id.* at 1568. Mental retardation sometimes occurs in infants with hydrocephalus; however, "[t]he mere presence of hydrocephalus does not necessarily imply a poor intellectual prognosis and does not preclude

independent existence." Mapstone, Rekate, Nulsen, Dixon, Glaser and Jaffe, *Relationship of CSF Shunting and IQ in Children with Myelomeningocele: A Retrospective Analysis*, 11 Child's Brain 112, 117 (1984). *See also* McLone, Czyzewski, Raimondi and Sommers, *Central Nervous System Infections as a Limiting Factor in the Intelligence of Children with Myelomeningocele*, 70 Pediatrics 338 (1982). If a child is treated with a shunt, then there is no necessary intellectual impairment.

It was the co-existence of hydrocephalus, the possibility of mental retardation, and the various other problems sometimes associated with myelomeningocele that led to the development of the discriminatory selection process at Oklahoma Children's Memorial Hospital that was used to determine which infants were to receive only the "supportive care," which involved denial of beneficial medical treatment leading predictably to death.

B. Social, Intellectual, and Other Nonmedical Criteria Were Considered in Determining Whether an Infant Should Be Denied Beneficial Medical Treatment.

When an infant with myelomeningocele presented at Oklahoma Children's Memorial Hospital, a "team" — consisting of a physician's assistant, a pediatrician, an orthopaedist, a neurosurgeon, an urologist, a nurse clinician, a social worker, physical and occupational therapists, and a psychologist — screened the child and the child's family; various diagnostic tests were performed. "If the child is found to have a lower lumbar or sacral lesion and no severe hydrocephalus or if there are no associated anomalies present, sac closure is recommended within a few days. If the lesion is at a high lumbar or thoracic level, severe hydrocephalus or other brain malformation is present, and/or other associated anomalies are noted, a

more formal meeting of the team is scheduled within 48 hours of admission." Gross at 452. Greater degrees of physical disability are associated with higher level lesions. The existence of a brain malformation indicates a greater possibility of mental retardation.

This formal "team meeting" to determine whether or not to provide an infant access to medical treatment occurred despite the fact, as the lead author of the report describing the selection process later conceded, that *"[b]abies considered to have a poor prognosis have a survival equal to that of babies with a good prognosis, if they receive early surgical treatment."* Gross, *Newborns with Myelodysplasia — The Rest of the Story*, 312 New Eng. J. Med. 1632, 1633 (1985) (emphasis added). Thus, the initial determination that some children ought to be considered for nontreatment bore no relation to whether or not treatment would enable the child to survive. It was based on the premise that some children *ought* not survive, even though they could if treated.

At the formal meeting "factors considered significant by Shurtleff et al (and to a lesser extent those considered significant by Lorber) were reviewed" by the team. Gross at 452.

Under Lorber's criteria, an infant would receive treatment unless he or she had a high level lesion, "gross enlargement of the head", *"severe paraplegia"*, or some other severe congenital defect. *Id.* at 450 (citing Lorber, *Early Results of Selection Treatment of Spina Bifida Cystica*, 4 Br. Med. J. 201 (1973) (emphasis added)). The presence of a high level lesion indicates a likelihood of a greater degree of physical disability; "gross enlargment of the head" might indicate a greater possibility of intellectual impairment. The use of "severe paraplegia" as a selection criterion certainly indicates that a prediction about the ability of a child to walk unaided would be a factor in deciding whether to provide the child with life-saving treatment.

Shurtleff's criteria differed from Lorber's "in that aggressive treatment was recommended for any infant, regardless of the level of the lesion, *if a good intellectual prognosis was noted.*" Gross at 451 (emphasis added). Shurtleff's criteria also included such factors as the existence of any major malformations that would preclude self-care as an adult, the economic and intellectual resources of the family, the distance the family lived from an appropriate facility, and commitments by social agencies to provide resources (such as a foster home or medical care costs) in determining whether or not a child would be treated. *Id.* (citing Shurtleff, Hayden and Lowser, *Myelodysplasia: Decision for Death or Disability*, 291 New Eng. J. of Med. 1005 (1974)).

In the selection process, the myelomeningocele team was also "influenced" by a pseudo-algebraic formula — QL = NE x (H + S) — published by Shaw in *Defining the Quality of Life*, 7 Hastings Center Rep. 11 (1977): "In the formula, QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family and S is the contribution from society." Gross at 456. It was the myelomeningocele team's view "that external circumstances are crucially important in the outlook for the newborn with myelomeningocele. Thus, the treatment for babies with identical 'selection criteria' could be quite different, depending on the contribution from home and society." *Id.*

Following an evaluation of a child and the child's family under these intellectual, social, and economic criteria, the myelomeningocele team made a recommendation for either "vigorous treatment" or "supportive care." *Id.*

"Vigorous treatment" consisted of prompt sac closure (and thus prevention of infection), the insertion of a shunt if hydrocephalus were present, and all other indicated therapies.

"Supportive care" consisted of keeping the infant comfortable until death occurred. There was no surgery to close the opening in the infant's back. When hydrocephalus was present, the cerebrospinal fluid was allowed to accumulate causing gross enlargement of the infant's head and compression of the brain. "Antibiotics are not given for infection and sedation is not prescribed." *Id.* at 452. Thus, raging infections would spread throughout the central nervous system, gaining access through the opening in the spine, and would go untreated; a child would not be sedated for relief of pain. The predictable result was death, which occurred in every case in the reported program in which only "supportive care" was provided.

The authors of the article that described the program stated that the final decision between "vigorous treatment" or "supportive care" was left to the parents; and if the child is deemed unworthy of treatment, but the parents still want their child treated, then "their wishes are followed unless the operative risk is considered a direct threat to the baby's life." *Id.* There is no indication, however, that the parents were informed of the nonmedical, intellectual, social, and economic factors that entered into the recommendation. Moreover, it is "unrealistic for a physician to expect a father (mother is generally still hospitalized) to make such a difficult decision at a time of terrible emotional trauma. Invariably, in these circumstances, families make a decision based on information that is given to them by the pediatrician, pediatric neurologist or neurosurgeon. The great likelihood is that any one of these physicians will have his/her philosophy concerning what should be done and, therefore, whether intentional or unintentional, the information will be skewed. It is, therefore, the physician that is responsible for the immediate decision for or against treatment." Epstein, *Meningomyelocele: "Pitfalls" in Early and Late Management*, 30 Clinical Neurosurgery 366, 366-67 (1983). *See also* Homer, *Selective Treatment*, 87 Am. J. Nursing 309

(1984). Indeed, Dr. Gross, lead author of the report describing the selection process, admitted that "it takes a great deal of courage on the amount of parents to say, in the face of a recommendation from a physician, that they wish to go counter to that. They certainly do not have the background at the time the child is born to really know what is expected." Sherwood, *"Who Lives, Who Dies?" — Part II*, Cable News Network Documentary (February 22, 1984). *See generally* H. Turnbull & A. Turnbull, *Parents Speak Out: Then and Now* (1984).

Even though the authors asserted that the "final decision" was made by the parents, it is therefore unreasonable to presume that the parents could have made an intelligent and informed decision at the time of the child's birth. Parents would almost always rely on the expertise of the myelomeningocele team and follow their recommendation. And there is no evidence that the team informed the parents of the various nonmedical criteria — including criteria that related to the parents' social and economic status, geographical location, their presumed ability to cope with a disabled child, and the projected impact of the child on family life — that formed part of the basis for their recommendation. The members of the myelomeningocele team were the true decisionmakers at Oklahoma Children's Memorial Hospital, not the parents.

In sum, the selection process at Oklahoma Children's Memorial Hospital involved conjecture and the use of a number of nonmedical criteria — intellectual capacity, degree of paraplegia, family wealth and resources, geographical location — that had nothing to do with whether beneficial medical treatment was available to preserve the child's life or to correct an impairment. To the extent that such nonmedical criteria were employed, the participants played judge, jury, and seer for the children they evaluated, in effect recommending death for those they deemed unworthy of life.

C. Recommendations for Denial of Beneficial Medical Treatment Led to the Death of Twenty-four Infants.

Sixty-nine infants with myelomeningocele were seen at Oklahoma Children's Memorial Hospital during the five years that the reported study was in progress. Only thirty-six (52%) of these infants were recommended for "vigorous treatment." [1] The remaining thirty-three (48%) were recommended for "supportive care".[2]

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[1] When screening an infant and making a recommendation, the myelomeningocele team considered the criteria first published by Dr. Shurtleff as significant. Gross at 451. However, during the same period, 87% of the infants with myelomeningocele who presented to Dr. Shurtleff at Children's Orthopaedic Hospital and Medical Center in Seattle, Washington, received surgical (vigorous) treatment. Shurtleff, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 164, 164 (1984).

[2] The nature and results of this selection program were subsequently criticized in the medical literature. "[T]he Oklahoma team is not ambivalent about giving only supportive care to 48% of the children.... They were not even ambivalent about not treating five children with L-5 sacral lesions: children who will walk with minimal bracing." Freeman, *Early Management and Decision Making for the Treatment of Myelomeningocele: A Critique*, 73 Pediatrics 564, 565 (1984). "Do the authors seriously contend that the child with a high thoracolumbar lesion does not have the potential for human relationships? If so, I would suggest that they attend some of the youth programs at the national Spina Bifida Association of America meeting and educate themselves further in this regard." Venes, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 162, 162 (1984). .... "The reader unfamiliar with children who have myelomeningocele would believe, after reading this paper, that half of these children (48%) can be expected to have such a wretched existence that they should not be allowed to live.... In the past five years, we have treated all newborns who have myelomeningocele with full therapy.... None of our patients are in a vegetative state: all appear to enjoy life; and all interact well socially.... A review of the school performance of our older children reveals that 53% are at grade level or above, and 33% are at grade level but with special help." Liptak, Masiulis, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 165, 165 (1984).

(Footnote continued on following page)

Five of the infants recommended for nontreatment by the myelomeningocele team at Oklahoma Children's Memorial Hospital nevertheless eventually received vigorous medical attention[3]. Although two of these five children died at nine and seventy-two days of age respectively, the other three are alive and well. "One preschool aged boy with a thoracolumbar level lesion is able to stand and is considered to be doing well for his age. Another has microcephaly and is developmentally delayed, but is healthy. ... The third child has moved to another state, the child's name has been changed, and we have no current information." Gross, *In Reply*, 74 Pediatrics 166, 167 (1984). When treated, therefore, the children recommended for nontreatment were indeed capable of survival.

(Footnote continued from preceeding page)

"I read with disbelief the article by Gross et al. .... In our hands prompt treatment of unselected patients with myelomeningocele ensures that 85% survive, and of the surviving children, 73% have normal intelligence, 74.5% are community ambulators, and 85% are continent of urine on clean intermittent catherization.... The published opinion of the Spina Bifida Association of America, an organization composed principally of parents of children born with myelomeningocele, is dramatically opposed to the management put forth by Gross et al. The documented suffering appears to be of lessor [sic] concern to these families while education, access to transportation, and eventual employment are major concerns." McLone, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 Pediatrics 162, 163 (1984). "The OCMH doctors quoted the writings of the Rev. Richard A. McCormick, Rose F. Kennedy professor of Christian ethics of Georgetown University, to support their selection method. But McCormick ... told *Newsday* that the OCMH rate of not operating on children with spina bifida is abusively high. They're abusing what I have said.'" Kerr, *Computing the Cost of Life*, Newsday, June 2, 1985 at 4, col. 1. "We would agrue that it is moral and ethically correct to treat all children born with a myelomeningocele and that no valid criteria exists for the selection of infants for nontreatment. McLone, *Results of Treatment of Children Born with a Myelomeningocele*, 30 Clinical Neurosurgery 407, 407 (1983).

[3] Of the remaining four infants recommended for "supportive care," three received delayed treatment and one moved to California at one month of age and was lost to follow-up. Gross at 453.

The twenty-four (35%) infants who were in fact denied medically indicated treatment during the five year period of the study all died within 189 days of birth. Gross at 453.

III. SECTION 504 WAS VIOLATED WHEN HANDICAPPED INFANTS WERE DENIED ACCESS TO MEDICAL CARE AT OKLAHOMA CHILDREN'S MEMORIAL HOSPITAL.

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794 (1982), provides in relevant part:

> No otherwise qualified handicapped individual in the United States, as defined in Section 706(7) of this title, shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

A "handicapped" individual is defined in 29 U.S.C. §706 (7)(B)(1982), as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such impairment, or (iii) is regarded as having such impairment." "An otherwise qualified handicapped person is one who is able to meet all of a program's requirements in spite of his handicap." *Southeastern Community College v. Davis*, 442 U.S. 397, 406 (1979).

Under the plain language of the Rehabilitation Act, therefore, the children subjected to the selection process were "handicapped individuals." *See United States v. University Hospital, State University of New York at Stony Brook*, 729 F.2d 144, 155 (2d Cir. 1984). They were "otherwise qualified handicapped individuals" because they were able to meet all the "requirements" of a medical program or activity — they could benefit from appropriate medical care, despite their handicaps. Moreoever, the selection process and treatment regimen that these

children were subjected to constituted discrimination in violation of the plain language of Section 504 of the Act.

A. Discrimination Between Infants with "Significant Handicaps" and Infants with "Minimal Handicaps" in the Initial Selection Process Violated the Plain Language of Section 504.

The first violation of Section 504 by Oklahoma Children's Memorial Hospital was the application of a selection process that permitted infants with a prognosis for a minimal handicap automatic access to medical treatment, while infants with a prognosis for a more significant handicap were placed in a formal selection process — despite the fact that "[b]abies considered to have a poor prognosis have a survival equal to that of babies with a good prognosis, *if they receive early surgical treatment.*" Gross, *Newborns with Myelodysplasia — The Rest of the Story*, 312 New Eng. J. of Med. 1632, 1633 (1985) (emphasis added).

This distinction drawn between an infant predicted to have a "significant handicap" and an infant predicted to have a "minimal handicap" — evidentially based on differing degrees of intellectual capacity and physical disability — clearly violated Section 504: It excluded an infant with a "significant handicap" from the participation in, and denied the infant the benefits of, the automatic medical treatment regimen accorded the infant with a "minimal handicap" for reasons based solely on the projected handicaps of the infant. *See generally* L. Kamin, *The Science and Politics of I.Q.* (1974).

B. Discrimination Among Infants with "Significant Handicaps" on the Basis of Inteilectual, Social, Economic, and Other Nonmedical Criteria Violated the Plain Language of Section 504.

Infants with a prognosis for survival with a significant handicap were compelled to meet other additional discriminatory criteria before they might be recommended

for access to medical treatment. These criteria included such factors as the predicted intelligence quotient (I.Q.) of the child, the degree of physical disability, the economic and intellectual resources of the child and family, the geographical proximity of the family to a medical facility, and the expected contributions to the child's care from home and society. Gross at 451, 456.

Using Lorber's criteria, the infant would receive only supportive care if "severe paraplegia" existed. Gross at 450; *see also* this brief at 9. This clearly discriminated solely on the basis of physical handicap, which is plainly contrary to the express purpose of Section 504.

Using Shurtleff's criteria, children with a good intellectual prognosis were recommended for vigorous treatment regardless of the level of the lesion. Shurtleff also considered the intellectual ability of the infant's parents in making a recommendation for or against treatment. Gross at 451; *see also* this brief at 10. The use of these factors clearly discriminated on the basis of mental handicap, contrary to Section 504.

Using Shaw's formula, the "natural endowment" of the infant is significant. Gross at 456; *see also* this brief at 10. "Natural endowment" would include both the projected intellectual capacity and the physical ability of the infant; both factors discriminated solely on the basis of handicap, in violation of Section 504.

The application of these criteria in the second phase of the selection process resulted in the discriminatory denial of treatment to infants based solely on the basis of their handicaps: The children who were recommended for and received only "supportive care" — food, water, and little more — were denied the benefits of, and participation in, the medical treatment regimen that was accorded those

children who were deemed worthy of care.[4] As a result, they died.

IV. CARLTON JOHNSON, AN INFANT WITH CONGENITAL DISABILITIES, WAS DENIED MEDICAL TREATMENT ON TWO SEPARATE AND DISTINCT OCCASIONS AT OKLAHOMA CHILDREN'S MEMORIAL HOSPITAL IN VIOLATION OF SECTION 504.

Carlton Johnson, now almost 3 years of age, was born on September 12, 1982. Carlton, a black male infant, experienced respiratory distress at birth and was found to have myelomeningocele with hydrocephalus, microcephaly, and anemia.

Progress notes made by myelomeningocele team members in Carlton's medical record stated that he was

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[4] The Secretary of the U.S. Department of Health and Human Services interpreted Section 504 to prevent just this sort of discriminatory medical practice:

> In the case of an infant born with myelomeningocele, for example, the treatment which must be considered is surgery to close the protruding sac to prevent infection and other potentially fatal consequences. The "handicap" is the physical and/or mental impairment the infant is regarded as likely to have in future life. To the extent the myelomeningocele itself or other complications (such as respiratory problems, infection, anesthetic risk, or other factors) present, in the exercise of reasonable medical judgment, contraindications to the surgery, the infant is not able to benefit, in spite of his or her handicap, from the surgery. However, if the surgery would be medically beneficial, in that it would be likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding infection or other fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is because of the handicap and in spite of the infant's being qualified to receive the surgery.

Dep't of Health and Human Services, Office of the Sec'y, *Nondiscrimination on the Basis of Handicap: Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1621, 1637 (1984).

"not a good baby" and that "neurosurgery [was] not enthusiastic about shunting the child and closing the defect." The medical records state that information was given to his mother, Sharon Johnson, and that she would make the final decision. Mrs. Johnson, however, said that "the only thing they told me was about a shunt, and this, you know, after they told me about six months, that he would live six months without it, and then with it, a year, and I just figured, what's the sense in — he already suffers, so why should he suffer anymore?" Sherwood, *"Who Lives, Who Dies?" — Part 1*, Cable News Network Documentary (February 21, 1984). This statement indicated that Mrs. Johnson was not given adequate information to make a reasoned and informed decision.

Once it was determined that Carlton would be denied medical treatment, he was transferred to a nursing care facility for custodial care. His medical expenses at the hospital and the nursing home were paid by Medicaid.

Section 504 was violated when Carlton was denied access to beneficial medical treatment and was instead transferred to the nursing home. Carlton is a handicapped individual within the definition of 29 U.S.C. §706 (7)(B)(1982). He was "otherwise qualified" because he was capable of benefiting from medical treatment. Therefore, Carlton was discriminatorily denied medical treatment solely by reason of his handicap, in violation of the plain language of Section 504.

On October 17, 1982, Carlton returned to Oklahoma Children's Memorial Hospital with severe but treatable problems. His medical records show that Carlton was now experiencing severe respiratory distress and periods of apnea (cessation of breathing). On admission Carlton was cyanotic (bluish), and his condition was listed as guarded. Further clinical examination revealed bilateral otitis media (ear infection) and dehydration. Physician's orders stated that there were to be no laboratory tests to monitor

his condition; there were to be no intravenous fluids to correct the dehydration; there were to be no antibiotics for the ear infection. If Carlton were to suffer a cardiopulmonary arrest, he was not to be put on a respirator and no drugs were to be used. The only intervention that was to be allowed in this life-threatening situation was suctioning, giving of oxygen, and cardiac compressions.

Fortunately, Carlton did not experience a cardiopulmonary arrest. The only medical care that Carlton received during his hospitalization was oral-gastric tube feedings. He received no antibiotics for his ear infection. His dehydration was not treated with intravenous fluids and routine laboratory tests to monitor his condition were not performed. Despite this lack of ordinary medical treatment, Carlton's condition improved after he was rehydrated through the tube feedings. His ear infection cleared on its own.

This outrageous conduct clearly violated the plain language of Section 504. Carlton was denied beneficial treatment for his severe dehydration and ear infection — conditions totally unrelated to his handicap — solely because of his handicap. There is no question that a non-handicapped infant would have been aggressively treated in this life-threatening situation. This is an obvious and clear example of exactly the discriminatory conduct that Section 504 was enacted to prevent.

Carlton's medical records indicate that, with the exception of an emergency room visit at which time a hernia was diagnosed, he was not seen again at Oklahoma Children's Memorial Hospital until a year later in October, 1983. At that time it was becoming increasingly clear that he was not going to die. Both his head and the "sac" on his back had become grossly enlarged before Carlton was referred to neurosurgery for closure of the spine and placement of a shunt to treat his hydrocephalus.

It was not until January 30, 1984, however, that his spine was finally closed. A shunt was placed on February 7, 1984, and his hernias were repaired on February 17, 1984. As a result of delay, Carlton's head remains greatly enlarged. Further evaluation is needed to determine the loss of intellectual capacity and loss of ambulation — and the greater educational and rehabilitative services he will need — that occurred as a result of the delays in appropriate treatment.

V. THIS COURT SHOULD ACKNOWLEDGE THE AUTHORITY OF FEDERAL LAW TO PROTECT BOTH INFANTS WITH DISABILITIES AND THEIR PARENTS.

For children with disabilities and their parents to invoke the authority of Section 504 in the face of such discriminatory treatment, and in order that the federal government should have the power to investigate and protect both infants with disabilities and their parents from such discrimination, this Court must recognize that Section 504 applies to discriminatory medical practices.

A. The Injunction Currently in Force Has Prevented the Federal Government from Investigating the Selection Process at Oklahoma Children's Memorial Hospital.

On February 24, 1984, The Association for Retarded Citizens of the United States, The Association for Persons with Severe Handicaps, The Spina Bifida Association of America, The Down's Syndrome Congress, Nat Hentoff, and Martin Gerry[5] filed a formal complaint with the

[5] Mr. Nat Hentoff is a columnist for the *Village Voice* and a former member of the Executive Committee of the New York Civil Liberties Union; Mr. Martin Gerry is former Director of the Office for Civil Rights of the United States Department of Health, Education and Welfare (1975-1977), and is presently counsel to Wednesday Group of United States House of Representatives and to several national parents and disabilities rights organizations.

United States Department of Health and Human Services and the Department of Justice that alleged the selection process at Oklahoma Children's Memorial Hospital violated Section 504. The complaint requested that the program be investigated and enforcement action taken.

On June 29, 1984, however, the Director of the Office for Civil Rights of the Department of Health and Human Services notified the complainants that the Department of Health and Human Services was precluded from taking action under Section 504 due to the injunction issued by the district court in *American Hospital Association v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984). *See* Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment"*, 1 Issues in L. & Med. 15, 38-39 (1985). Consequently, no investigation of the selection process has been undertaken by the federal government.

Any similar decision by this Court holding that Section 504 does not apply to medical practices would permanently render the federal government powerless to investigate and to correct egregious forms of discriminatory conduct — even when performed by state actors in state institutions that receive federal funds, such as Oklahoma Children's Memorial Hospital.

There would be no question that the federal government could appropriately investigate and take measures to correct discriminatory medical decisionmaking based on the race of children in state-run, federally funded institutions. *See* Jones, *Bad Blood: The Tuskegee Syphilis Experiments* (1981). To hold that the federal government may not take similar steps for medical discrimination based on disability would be contrary to the intent of Congress and the plain language of Section 504.

B. Section 504 Must Apply to Discriminatory Medical Practices to Protect Parental Rights.

"This Court's decisions have by now made plain beyond the need for multiple citation that a parent's desire for and

right to 'the companionship, care, custody, and management of his or her children' is an important interest that 'undeniably warrants deference and, absent a powerful countervailing interest, protection.'" *Lassiter v. Department of Social Services*, 452 U.S. 18, 27 (1981) (citing Stanley v. Illinois, 405 U.S. 645, 651 (1972)).

At Oklahoma Children's Memorial Hospital, the myelomeningocele team purported to leave the final choice between supportive care or vigorous treatment to the parents: "If a pessimistic evaluation and prognosis has been offered the family but they still wish treatment, their wishes are followed unless the operative risk is considered a direct threat to the baby's life. (The reverse situation, refusal to consent to recommended surgery, did not occur.)" Gross at 452. But it is utterly unreasonable to expect the vast majority of parents to overrule the team's recommendation at a time soon after the traumatic birth of their disabled child. There is no indication that the parents were ever informed of the nonmedical intellectual, social, and economic criteria that formed the recommendation. *See* this brief at 12. The decision for treatment or "supportive care" was in fact made by the members of the myelomeningocele team in the form of a "recommendation" that almost all parents — in shock and without the emotional or informational resources to contest the "recommendation" — mechanically followed.

The recommendation of the team was based on criteria that violated the plain language of Section 504. When the infant was denied access to medical treatment in this manner, the parents' right to the care, custody, and management of their child was violated: The children who received only "supportive care" all died, completely severing the parent-child relationship. In this fashion, parental rights were denied on the basis of discrimination against their children with disabilities. Yet if Section 504 were held not to apply to such discriminatory medical

practices, then parents in such circumstances will be unable to claim the support of federal law to vindicate their rights and interests.

C. The Federal Government Must Have the Power to Investigate Allegations of Discriminatory Conduct in All Federally Funded Programs.

The Child Abuse Amendments of 1984, Pub. L. No. 98-457, tit. 1, §§121-28, 98 Stat. 1749, 1752-55 (codified as amended at 42 U.S.C. §§5101-5103 (Supp. 1985)), treat the withholding of medically indicated treatment from disabled infants with life threatening conditions as child abuse. As a condition of receiving state grants under the Child Abuse Prevention and Treatment Act, the State must have a procedure in its child protective service system to respond to reports of such abuse. If the state agency does not investigate incidents like the selection process at Oklahoma Children's Memorial Hospital, then it may be denied federal funds.[6]

The selection program at Oklahoma Children's Memorial Hospital, a state institution, was itself funded by federal funds insofar as the hospital and physicians were paid through Medicaid for services rendered to Carlton Johnson and other children subject to the selection process. Yet if Section 504 does not apply to discriminatory medical practices, then the federal government will not have the authority to stop the use of its funds to reimburse hospitals and physicians engaged in such discriminatory neglect. At the same time, it would be *required* to stop funding child

[6] It should be noted that there is no indication that the Oklahoma Children and Youth Services had even investigated the abusive practices at Oklahoma Children's Memorial Hospital, although they were a matter of public record. The Oklahoma Children and Youth Services and Oklahoma Children's Memorial Hospital are both under the authority of the Director and the Board of Commissioners of the Oklahoma Department of Human Services — the individuals ultimately accountable for the abusive practices at the hospital.

protection agencies that fail to pursue such instances of discriminatory child abuse. Such an absurd and inconsistent result can only be avoided by recognizing that Section 504 applies to discriminatory medical practices.

CONCLUSION

It is submitted that Section 504 of the Rehabilitation Act of 1973 should be held to apply to discriminatory medical practices and that the holding of the Court of Appeals for the Second Circuit to the contrary should be reversed.

Respectfully submitted,

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